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ABSTRACT

This practicum provided support to isolated parents whose institutionalized children with mental handicaps were being returned to the community. It focused specifically on an isolated single parent father with a teenage daughter. The father joined a parent group for support. Support was provided to the father by assisting him in accessing information on community services for the child, exploring the development of new services, individual counseling including unlimited access by telephone, encouragement and support to join a parent self-help group, development and practice of advocacy skills, role-playing preparation prior to meetings with government officials, debriefing following such meetings, and reinforcement and celebration of successful advocacy efforts. Following support and training, growth was noted in the father's knowledge of community services, his self-confidence and empowerment, his ability to develop a written community living plan for the child, and his use of advocacy skills to secure his child's future. Other members of the parent group showed similar gains, but had not moved as far along in the process. Appendices contain pre-interview and post-interview guiding questions and an individual community living plan which addresses physical health, communication, psychological health, behavior, self-care skills, community integration, and projection of required services. (Contains 31 references.) (JDD)

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Planning For Deinstitutionalization: Supporting A Single Parent Father

by

Margaret Elizabeth Brown

Cluster 40

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A Practicum I Report presented to the
Ed.D. Program in Child and Youth Studies
in Partial Fulfillment of the Requirements
for the Degree of Doctor of Education

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PRACTICUM APPROVAL SHEET

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This practicum report was submitted by Margaret Elizabeth Brown under the direction of the adviser listed below. It was submitted to the Ed.D. Program in Child and Youth Studies and approved in partial fulfillment of the requirements for the degree of Doctor of Education at Nova University.

Approved:

March 13, 1993
Date of Final Approval of Report

Mary Ellen Sapp
Mary Ellen Sapp, Ph.D., Adviser

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The writer is indebted to the parents of institutionalized children with mental handicaps who, while preparing for their children's return to the community, participated in this practicum. Their committment to their children and their willingness to help and support each other in their struggle was impressive. The active participation of the single parent father, who was the primary focus of the practicum, was particularly rewarding. Without the full co-operation of these parents, this practicum could not have been accomplished. For this, the writer expresses sincere appreciation to all the participants.

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ABSTRACT

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Deinstitutionalization/Mental Handicap/ Parent Counselling/ Fathers/ Single Parents/ Community Living/ Self-Help Groups/Advocacy

This practicum was designed to provide support to isolated parents of children with mental handicaps living in institutions who were being returned to the community. Initially the focus was on an isolated single parent father whose teenage daughter was returning to the community. Later the focus shifted to include a parent group which the single parent father joined for support.
The writer provided intensive support to the single parent father by assisting him in accessing information on existing community services for the child, exploring the development of creative new services, individual counselling including unlimited access by telephone, encouragement and support to join a parent self-help group, development and practice of advocacy skills, role-playing preparation prior to meetings with government officials, debriefing following such meetings, and reinforcement and celebration of successful advocacy efforts.
Analysis of the data revealed that following support and training, growth was noted in the single parent father's knowledge of community services, in the ability to develop a written community living plan for the child, and in using advocacy skills to secure his child's future. The parent exhibited greater self confidence and empowerment. Other members of the parent group showed similar gains, but are not yet as far along in the process.

* * * * * * * * *

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30 September 1992 Margaret E. Brown

CHAPTER I

INTRODUCTION

Description of Work Setting and Community

One of the highest rates of institutionalization of children with disabilities in Canada exists in a small maritime province. In the late 1960s the provincial government built four small institutions, in different locations, for children with mental handicaps. In recent years, pressure from parent and advocacy groups has been brought to bear on the government to consider closing the institutions and providing the full range of support services within the community for these children and their families, as well as for those families whose children have always lived at home. Despite declining enrollments and increasing costs, the provincial government resisted such a change until the spring of 1991 at which time closure of all four children's institutions between 1992 and 1994 was announced.

Since that time, families of the children in the institutions have struggled to come to grips with the full meaning of deinstitutionalization

for their children and how they as parents need to respond. One avenue of support available to parents of children with mental handicaps has been contact with community-based special education consultants for assistance and advice. The reasons for consultation included such services as accessing basic information about the disability, family adjustment counselling, development of individual education (or program, family, community living, or transition) plans, development of advocacy skills, development of the skills and techniques for management of specific child behaviours, and the like.

Parents of children with mental handicaps often need to contact special education consultants for training, counselling and support. While group counselling is typically an effective intervention for most parents of children with handicaps, in some instances a parent finds it difficult or impossible to meet with a group. The nature of the problem being addressed, and the particular characteristics and interests of the family concerned, determines whether the intervention will be with the individual family or with a group of families.

Because the community in not always responsive to the needs of families with children with mental handicaps, parents frequently request assistance with developing the advocacy skills necessary to access and to monitor the appropriate health, education, and social support services required by their children and their families. Although community-based special education consultants are not plentiful in this province, those who exist can provide this service to parents or parent support organizations. In that capacity, the writer is in contact with many parents who have children with mental handicaps.

Writer's Work Setting and Role

Those involved included the children with mental handicaps and their families, the Community Services Department of the provincial government, parent advocacy and support organizations, private consultants in special education. The parents of children returning to the community were typically angry, confused, and afraid, and were unsure how to proceed on behalf of their children. The Community Services Department of the government was anxious to have individual community living plans drawn up and implemented as soon as possible, preferably by the parents but if this was not possible or feasible, then the provincial government (Department of Community Services) would assume the responsibility. The provincial parent advocacy association was forming parent support groups and providing assistance to the parents in their efforts to plan appropriately for their children. A private special education consultant in the area was involved with assisting the parent association with parent training and advocacy as well as with individual parent's requests for support in this endeavour.

The role of the writer as a private special education consultant was to respond to requests from any interested parent, group of parents, association or government personnel, to assist in the deinstitutional-ization process.

CHAPTER II

STUDY OF THE PROBLEM

Problem Description

Four regional institutions for children with mental handicaps existed in the province. In the spring of 1991 the provincial government announced the closure of the institutions and the return of the children to the community. Government officials stated that current best practices indicated that children would thrive better in the community than in an institutional setting, and that the institutions were not being closed as a cost-saving measure. However, not all parents of children who were living in the institution believed either or both of the government statements.

Approximately 80 children were to be involved in the transfer to the community between 1992 and 1994. The children had lived away from their families from between two and eighteen years. Some children had been wards of the province since birth and had no connection with their natural families. Initial responses to the announcement of institution closures ranged from disbelief and dismay, to anger and outrage, to confusion and fear.

The provincial government requested that the parents of each child develop an individualized community living plan for their child, outlining the full range of support services (health, education, social, recreational, spiritual, etc.) that were required. Individual parents stated that they are confused and fearful, particularly because they felt they lacked the necessary information, knowledge, and expertise to adequately plan for their child's future in the community. Yet, that was what was being required of them.

The municipal governments responsible for the provision of support services were not always responsive or cooperative in the deinstitutionalization process. Since the provincial government had been totally responsible for the children's care and services while they lived in the institutions, the municipalities typically had not developed the full range of services in their communities and preferred to have the provincial government retain responsibility for the financial burden.

Original placement of the children in the institutions usually had been precipitated by the high level of needs of the children and the low level of services in the community. Thereafter, parents had little reason to be aware of, or involved with, the provision of support services in the community, as their children received total care in the institutions. Consequently, parents now lacked the knowledge and experience to be able to make judgements about what support services their daughters and sons required to live and grow successfully in the community.

While most parents turned to each other for support and encouragement, especially through such organizations as the provincial parent advocacy association, some parents remained disconnected from any support network and were reluctant or unable to engage with others.

There appeared to be little concern on the part of the provincial government or others to provide support to these underserved parents.

Reasons for these parents to remain disconnected included the following: a) a lack of awareness of others with similar circumstances and a feeling that "I am the only one in the world that this is happening to"; b) a sense of being different in some way and feeling they do not "fit in" with other parents; c) living in a geographically remote area which limited access to other parents; or d) an aversion to any type of group activity and a strong preference for acting on their own. For the purpose of this practicum, the term "isolated parent" referred to such a parent.

The problem was that isolated parents of institutionalized children with mental handicaps were disconnected from support networks and felt unprepared for the task of working with government officials to develop a deinstitutionalization or community living plan for their sons and daughters. For most of the parents, having their children return to living within the natural family was not an option. Arrangements for alternate community accommodations, such as specialized foster care or a small family-like group home for three or four children, needed to be made.

Problem Documentation

In the spring of 1991, the provincial government announced the closure of the four regional centers for children with severe mental handicaps; these children were being returned to the community between 1992 and 1994. The children ranged in age from five to 18 years, and had been institutionalized from between one and 18 years. Since the

announcement of the closure, a provincial parent advocacy organization had provided support to the parents. Interviews with three senior staff members of the parent advocacy association, the Executive Director, the Family Support Co-ordinator, and the Family Support Program Development Officer, indicated that the most pressing problem for parents was knowing how to develop a suitable plan for their children. While many parents had organized into successful support groups and were benefitting from the various seminars and workshops offered by the parent association, a few isolated parents needed to access individual support to enable them to develop an appropriate community living plan for their son or daughter.

In addition to providing input and assistance to the parent association in its efforts to build and support parent groups, the special education consultant received requests from three isolated parents who required individual assistance with the task of developing a community living plan for their children.

Communication with Department of Community Services officials in the Services to the Mentally Handicapped Division confirmed that some isolated parents had not yet developed community living plans for their sons and daughters. Further, parents were being pressured to either exercise their rights and responsibilities with regard to their sons and daughters, or forfeit those rights to the government. Unless parents submitted their plans within the next three months, that is, by the end of June 1992, the task would be taken over by the Department and parents would lose control of the decision-making process for their children. In essence this meant that the government would place children wherever a residential "space" existed, which might be a group home far removed

from the natural family, or in a foster care placement. If that were to occur, opportunities for parents to influence the quantity and quality of education and support services would be limited at best.

Causative Analysis

The provincial government's decision to close the children's institutions was in many ways a mixed blessing. On the one hand, advocates of community living were pleased that the government finally had responded to the long-standing pressure to do so. In fact, most other Canadian provinces closed their children's institutions some years earlier, while this province had maintained their existence, largely for political reasons. On the other hand, the arbitrariness of the decision and the speed with which the deinstitutionalization was progressing caused some concern. Given the present difficult economic situation in the country as a whole, it was difficult not to suspect the government's recent enlightenment in terms of deinstitutionalization. The fear was that the closure decision was but a thinly veiled cost-cutting measure for the government, and that the necessary funds would not follow the children to their home communities.

The municipal governments in many instances were not particularly responsive or cooperative in the development of support services for the children returning to the community. Since the children with the greatest needs typically were removed from the community to the institutions, the onus of developing appropriate support services was lifted from the municipalities. Now that they were required to assume that responsibility,

their lack of experience and also the present difficult economic climate created a situation of at least subtle, and sometimes quite open, resistance to the return of these children to their communities.

As part of the preparation for the return of the children to the community, their parents were required by the provincial government to develop a deinstitutionalization, or community living, plan for their daughters and sons. While many parents willingly participated in the task, for some it was a very onerous task, not because they were unwilling, but because they felt inadequate to meet the demands of the task.

One of the reasons for some parents' reluctance was their lack of experience with the existing community services because their children had been served in the institutions for many years. They had no reason or need to be interested or even aware of the available community services. Consequently they had little basis for making informed decisions about their child's present and future service needs.

Parents were generally fearful of having their children returned to the community. It was usually expert professional advice that had persuaded them to institutionalize their child in the first place, with safety, security, and high quality services unavailable elsewhere being the key elements of the argument. Now much of the same argument was being used to persuade parents to accept deinstitutionalization.

The timeline put in place by the provincial government left parents feeling hurried. It was barely one year since the closure announcement was made, and substantially less than that since the government articulated their plan for the sequence and dates of closure of the various institutions. Now parents had to put together the community living plans for their children within the next three months or lose the right to do so to

the government. For some parents this was an overwhelming task in a very short period of time.

For those parent who were experienced and/or comfortable working with other parents in groups, the learning process could be facilitated. However, not all parents felt comfortable or supported in groups, and indeed some feel quite threatened and intimidated in groups. As well, it was not unusual for some individuals to be more successful in a one-to-one learning situation than in a group. At that time, there had been little opportunity for the parents to find individual support to learn to be a meaningful participant in the deinstitutionalization process of their sons and daughters. They constituted a small, but definitely unserved, group.

One such situation was identified where a single parent father was anxious to participate in the deinstitutionalization process for his thirteen year old daughter, but felt he had an inadequate knowledge base to make informed decisions regarding his daughter's needs, and also felt uncomfortable and unable to participate in the existing parent groups. The government had issued the ultimatum that they would take over the planning for his daughter in June 1992 if he had not developed and negotiated a satisfactory community living plan for her by that time. This father needed information about services in the community, assistance with the planning process, and advocacy skills to be able to successfully assume the parenting responsibilities he clearly wanted to exercise. At that point he was an isolated parent who was fearful of the future his daughter faced and frustrated with the pressure being exerted by the provincial government.

Relationship of the Problem to the Literature

Parents were reluctant to consider community placement for their children after they had been institutionalized. Parents were generally uninformed about the nature of community services such as group homes. Insufficient community services and lack of coordination between the institution and the community led to deinstitutionalization failure. Parents were afraid and confused by the change in professional attitudes and advice from promoting institutionalization in the past to promoting community placement now.

Deinstitutionalization

When faced with the possibility of deinstitutionalization of their daughters and sons, parents' reactions tended to be mixed. Spreat, Telles, Conroy, and Feinstein (1987) found that nearly 60% of the parents would not under any circumstances agree to deinstitutionalization, and a further 36% would agree only if adequate security, active programming, and adequate medical services were guaranteed. Scheerenberger (1987) described the initial reaction of parents as being mostly negative, regardless of their knowledge and support of the principle of normalization. They believed that the goals of normalization could best be met in the institutions. However, Black, Cohn, Smull, and Crites (1985) attempted to identify factors contributing to requests for institutionalization and the need to design effective community interventions. They found that "the key to reducing the risk of institutionalization is to provide a range of effective community services

targeted to the needs of both the retarded adults and their families" (p.275).

Feinstein (1986), in reviewing the Pennhurst Longitudinal Study and making comparisons to the Canadian scene, noted that the impact on families of the Pennhurst closure was startling. Based on interviews with 134 families before and after their relatives moved to the community, 55% were opposed before the move and only 5% were opposed after. Equally important, before the move less than 30% agreed with the move, and nearly 90% agreed after the move. While these data and others (Gallagher, Beckman, & Cross, 1983) indicated that deinstitutionalization was associated with increased stress on the parents involved, none of the studies referred to how parents were involved in the process, nor did they indicate what interventions, if any, were available to parents.

Gallagher, Beckman, and Cross (1983) noted that deinstitutionalization was not without its costs to parents, and was often associated with increased stress to parents. Many parents whose child with a handicap was institutionalized based upon acceptance of certain concepts and assumptions held by professionals and society at large, were now being asked to accept complete changes in expectations and assumptions (Avis, 1978). Avis argued that inadequate communication regarding the new phrases, concepts, and services that are replacing the old, was part of the cause of the discomfort. Families who made the decision for institutional placement a long time ago had a particular backlog of lack of communication which the practices of the institutions through the years engendered. Thus, they had not had the opportunity to incorporate new ideas and to absorb the implications and possibilities (Avis, 1978).

Parent Involvement in Planning

With respect to the development of plans for an institutionalized person to return to the community, Avis (1985) recommended that the plan be a sensible guide and an individualized plan for activity and leisure which could be implemented and would sustain questioning. However, she cautioned that "we do not get so entranced with making our plans and documenting our efforts that the life of the person behind such plans is overshadowed" (p. 197).

Turnbull (1985) articulated the fears held by many parents of older handicapped children living in the community, when he described his son soon passing from public school to adult services - a school system that must serve everyone to a nonsystem of multiple programs with usually inconsistent goals, functions, eligibility criteria, funding and governing authorities, and accountability.

Extreme stress has been reported by some fathers of autistic children (Warren, 1978; Greenfeld, 1979a, 1979b) in response to the inadequacy of the social support services available to meet the needs of their children in the community. In reviewing the work of Warren (1978) and Greenfeld (1979a, 1979b) and others knowledgeable in the area of stress experienced by fathers of children with severe disabilities, Meyer (1986) stated that:

> While it is uncertain how many other fathers of children who are autistic or otherwise handicapped agree with Warren and Greenfeld that society is methodically killing their children, the two fathers speak strongly and clearly about the stress, frustration, and rage felt by many fathers of severely handicapped children towards

society and a social service system ostensibly designed to help their children (p. 61).

Emerson (1985) suggested that evaluation needs to play a significant role in the monitoring and shaping of responsible and accountable community service systems. He offered three areas that need to be included in evaluation studies of the deinstitutionalization process:

1. "Outcomes significant for the quality of life experiences of persons with handicaps, including social indicators of distributive justice, the extent of personal social integration in the life of the community, and the personal satisfaction and lifestyles of the individuals with mental handicaps" (p.283).

2. "The direct measurement of the environment, specifically, the extent to which the aims of deinstitutionalization have been incorporated into the physical and psychosocial environments of community-based programs" (p. 283).

3. "The utilization of evaluation designs adequate to answer the questions posed" (p. 283).

Role and Experience of Fathers

As this practicum focussed primarily on a single parent father, an examination of the relevant literature on fathers was included. While there has been an explosion of research on fathers in the past few years, still relatively little is known about fathers of handicapped children. (Wikler, 1981). Bristol and Gallagher (1986) in discussing the role of fathers within families that include a child with a handicap noted the relative paucity of research on fathers in any context. Research on single parent fathering was even more limited. Pederson, Rubenstein, and

Yarrow (1979) stated that there were virtually no systematic studies of the type, amount, or sources of support that fathers themselves needed to adapt successfully to having a child with a handicap. It appeared that little has changed since that time.

In terms of father involvement in the family, Gallagher, Cross and Scharfman (1981) indicated that both mothers and fathers of children with developmental disabilities believed that it was appropriate for fathers to be involved in the problems of their children. This study further suggested that fathers appeared to be willing to take a more active role, although both parents were unsure of what that role should be. Gallagher, Scharfman, and Bristol (1984) found that despite the increased demands posed by having a child with a developmental disability in the family, fathers of young children with developmental disabilities did not help mothers with family tasks any more than did comparable fathers of children without handicaps. So it would seem that although fathers were willing, they did not know how to be involved with the problems posed by the child, and consequently helped with the family tasks in the same way as did fathers of children without handicaps.

The nature of previous experiences of parents, particularly fathers, of children with mental handicaps determined to some extent how they coped with the tasks associated with later events in their children's lives. In a study of families with young children with handicaps, Parke (1986) noted that mothers were more likely to use informal support networks than fathers, whereas fathers were more likely to use formal agencies for information, suggesting the need to distinguish between formal and informal support systems, and to ensure the provision of formal support systems for families including fathers. Meyer (1986) believed that there

was a growing realization among parents and professionals in special education of the need to address the concerns of fathers of handicapped children. Because organizations for parents and their children with handicaps offered fewer services for fathers, and they requested and obtained less participation from fathers, fathers had fewer opportunities to share their concerns and reduce their stress than did mothers.

Parents of older children with mental handicaps reported feeling less supported, more isolated, and more in need of expanded services than fathers and mothers of young children with mental handicaps (Suelzle & Keenan, 1981). Roos, McCann and Addison (1980) indicated that parents of adults with mental handicaps who had been institutionalized, frequently found themselves unsure of appropriate goals or programs for their sons and daughters. Meyer (1986) further noted that while programs for new fathers of children with handicaps could provide much-needed services to traditionally underserved family members, programs that addressed fathers' needs and concerns were required throughout the family life cycle. Again it seemed that the experience of fathers was notably different from that of mothers and was likely to have an impact on fathers' ability to participate successfully in later life events of the child.

Bristol and Gallagher (1986) stated that because so little was known about the optimum role of fathers in facilitating the development of their children with handicaps, caution was advised in devising intervention programs. They specifically stated that "respect for family cultural values and beliefs requires the encouragement of types and levels of paternal involvement with the child and the child's program that meet the families' real needs, rather than the convenience or bias of the intervention staff" (p.95).

With reference to children who were institutionalized, Hourcade and Parette (1986) reported that a lack of financial and programmatic resources to provide for the child adequately may make it impossible for the family to maintain the child at home. They further noted that according to the superintendents, teachers, psychologists, and social workers in the institutions, less than half the parents participated in the educational or habilitative programming for their children. Meyer's (1986) study revealed that parents typically felt a sense of both loss and relief resulting in the often experienced guilt and ambivalence. This study further noted that when the child was institutionalized, parents lost the opportunity of maintaining an active parenting role and often experienced great anxiety as a result.

Summary

In summary, the literature indicated that deinstitutionalization initially caused stress and confusion in parents whose children were affected. However, after the fact, parents were typically satisfied with having their daughters and sons living in the community. The literature further described parents as being fearful of engaging in the planning process for their children because they felt inadequate to satisfactorily accomplish the task, even though the plan was in reality a sensible guide to providing the child with a living arrangement that promoted personal satisfaction. Having the competence to develop and evaluate individualized plans for one's child seemed to be largely dependent upon the parent's earlier experience and support. And finally, the literature clearly presented a picture of the difficulties faced by fathers of children with mental handicaps. While fathers may be willing to be involved with

the child with a mental handicap, they did not know how to be involved. Further, with few services to support fathers, they tended to become isolated. The requirements of the parenting role, and particularly the fathering role, the effects of institutionalization, and the additional stress of the deinstitutionalization process, collectively created serious difficulties for parents of children returning to the community from the institutions.

CHAPTER III

ANTICIPATED OUTCOMES AND EVALUATION INSTRUMENTS

Goals and Expectations

The overall goal for this practicum was to enhance the integration of newly deinstitutionalized children, their families, and the community to achieve as fully functioning status for all as possible. Since isolated parents of institutionalized children with mental handicaps were disconnected from support networks and felt unprepared for the task of working with government officials to develop a deinstitutionalization or community living plan for their sons and daughters, a creative approach had to be taken to address the needs of this underserved group. As families are the bridge between the child and the government and/or community, isolated parents had to either have or acquire the skills to understand the child's strengths and needs, to understand the available community service system, to engage in appropriate planning for the child, and to build the necessary advocacy skills to access and monitor the community services required by the child.

Expected Outcomes

The following specific goals and outcomes were projected for this practicum.

Evidence. The provincial parent advocacy association reported that while most parents were working well together in groups, a few parents were isolated by virtue of certain characteristics and were in need of individual counselling and support to develop a suitable community living plan for their children.

Outcome 1. After the practicum implementation, the isolated parent(s) of each child will have prepared a suitable community living plan.

Evidence. The provincial parent advocacy association, with confirmation in the literature, indicated that parents whose children had been institutionalized were unfamiliar with the types and quality of health, education, and residential/housing services available in the community.

Outcome 2. After the practicum implementation, isolated parents will be familiar enough with the available services to have made appropriate choices and decisions for and with the child.

Evidence. The provincial parent advocacy association indicated that isolated parents did not attend group parents support meetings.

Outcome 3. After the practicum implementation, the isolated parent(s) will have attended at least two group parent meetings.

Evidence. The provincial government officials indicated that if the individual parents who had not yet developed plans for their children did not do so within three months, the government would take over responsibility for planning for the children.

Outcome 4. After the practicum implementation, the isolated parent(s) will be empowered to retain the parental role of primary advocate and decision-maker for and with their child.

Evidence. The provincial parent advocacy association indicated that isolated parents were fearful and unsure of how to work with the government to plan and access services for their child.

Outcome 5. After the practicum implementation, the isolated parent(s) will have participated with government officials in at least two meetings regarding the planning of services for their child.

Evidence. The provincial government, and to some extend the provincial parent advocacy association, had no mechanism for addressing the particular needs of the isolated parents and seemed unable to prevent the parent from losing control over the decision making process for themselves and their children.

Outcome 6. After the practicum intervention, a new and successful model of intervention for supporting isolated parents in the deinstitutionalization process will have been demonstrated.

In summary then, it was expected that after the successful implementation of the practicum, the integration of newly deinstitutionalized children, their families, and the community would be

enhanced as previously isolated parents were able to participate meaningfully in the development and implementation of community living plans for their children and become strong advocates for their children.

Measurement of Outcomes

The following tools and techniques assisted in the evaluation of the success of the intervention:

1. A pre-interview was conducted with the isolated parent to assess his level of knowledge regarding family values, child's needs, available services, and possible creative solutions. The interview was guided by eight general open-ended questions with the opportunity to add probing questions as appropriate (see Appendix A). The interview was conducted orally in surroundings comfortable to the parent, and with unlimited time available so as to allow the parent to fully express his views without feeling hurried.

2. A post-interview was conducted in a similar manner to the pre-interview regarding the same topics to assess growth in the four targeted areas (see Appendix B).

3. Documentation of participation in parent support groups meetings was maintained. The parent was asked to report orally, and where possible in writing, on the highlights of the parent meetings he attended. As written records are a vital advocacy strategy to be encouraged in all parents, it was therefore preferable to an oral report. However, it was recognized that for some parents writing might be a difficult or impossible task under the circumstances.

4. Documentation of participation in planning meetings with government officials was maintained. The parent was asked to report orally, and where possible in writing, on the highlights of the planning meetings he attended with government officials.

5. An appropriate planning document, individual community living plan, was to be produced (see Appendix C). The product was to be an appropriate community living plan for his daughter, to be used as the basis of the negotiations with the provincial government for the required community services.

Mechanism for Recording Unexpected Events

In addition to the above measures of the outcome the writer kept a log of the important features of each session with the parent and was particularly careful to record any unexpected events for later inclusion in the analysis of the practicum implementation.

CHAPTER IV

SOLUTION STRATEGY

Discussion and Evaluation of Solutions

The problem addressed by this practicum was that isolated parents of institutionalized children with mental handicaps were disconnected from support networks and felt unprepared for the task of working with government officials to develop a deinstitutionalization or community living plan for their sons and daughters.

A number of possible solutions were considered in an effort to select the best single or combination of solutions to produce the most successful outcome. Black, Cohn, Smull and Crites (1985) suggested that parents needed to be provided with information on community services and support when they were in the position of making decisions for the child. This appeared to be a necessity in this case given the information from parents themselves and from the provincial parent advocacy association.

Berger and Foster (1986) indicated that interventions needed to increase family members' ability to deal with service agencies and to build and maintain social network contact and involvement. This appeared to have a practical working strategies component as well as an advocacy

component. There appeared to be consistency with the needs as defined in the problem as well as with other parts of the literature. Interventions that increased parents awareness of the services that were available and that developed strong advocacy skills were solutions reiterated by Krauss (1986).

Meyer (1986) and Parke (1986) suggested that interventions needed to address fathers' concerns throughout the family lifecycle, and needed to increase fathers participation in support networks. Interventions also needed to address the fact that fathers of older children with mental handicaps had an increased need to reduce isolation and receive support (Suelzle & Keenan, 1981).

Summers, Behr, and Turnbull (1989) recommended providing education and information for the parent, facilitating parent involvement in social support or self-help groups, and improving parent-professional interactions.

Taking a much more flexible approach, Taylor, Knoll, Lehr, and Walker, (1989) promoted interventions that adopted a "whatever it takes" policy that placed much of the control for services into the hands of the parents and which was flexible enough to respond to the unique situation of each family. In a similar vein, Goldfarb, Brotherson, Summers, and Turnbull (1986) recommended interventions that included a taking stock-taking component which evaluated the parents roots, values, strength to cope, social support, and professional support; and a problem solving component which included communication, problem definition, brainstorming, choosing alternatives, action, and taking charge.

While all of these strategies gleaned from the literature were plausible solutions, others that were considered, but were less preferable,

included having the isolated parent join a counselling group for parents of children with mental handicaps despite discomfort with it in an attempt to overcome the discomfort; pairing up the one parent with only one other parent who was likely to be compatible; encouraging the parent to generate a plan without assistance; or relieving the parent of the burden and delegating the task to the government officials.

Description of Selected Solution

The goal was to provide one or more isolated parents with the necessary support to learn to develop a community living plan, to ensure the implementation of the plan, and to become a strong advocate for the child. The primary subject identified for this study was a single parent father whose 13-year-old daughter would be leaving the institution in the fall of 1992. As other isolated parents were identified in this geographic region, they were included in the practicum as appropriate. Three main intervention tools were used, individual counselling, information and support. The individual counselling was related to developing the advocacy skills necessary to access and monitor the services needed by the child. The information was related to gaining a sound base from which to make decisions regarding the child's educational, health, housing, recreational, and spiritual needs. Support was related to the information gathering process and to the development of the individual advocacy skills as the parent(s) began to practice them in parent group sessions and later in meetings with government officials.

The success of this practicum occurred because the intervention was designed to match the identified needs of the isolated parent. Further, this intervention had been requested by the parent, rather than imposed by someone else. The single parent father and his daughter, prior to her institutionalization, had been clients of the writer. In addition, this parent was highly committed to his daughter and willing to work hard to see that her needs were met in the best possible way.

The intervention initially was focussed on one parent, the identified single parent father described above. It was at the point of the second component of the intervention that other parents sought inclusion in the practicum strategies being employed and were willingly accommodated.

Individual counselling was an effective technique for helping parents of children with mental handicaps with a variety of aspects of their care. A leadership role was required to support isolated parents in this instance. Typical counselling and support failed in the past and resulted in the child being placed in the institution. A more intensive approach was required for the parent to successfully reclaim his rightful role as parent and advocate for his daughter.

The following components of the intervention seemed appropriate for the special education consultant/counsellor:

1. A willingness to explore with the parent all aspects of service and support (health, education, social services, recreation, spiritual, etc.) so that the parent could make informed choices for the child's future.

2. A willingness to teach advocacy skills to the parent and to coach as the parent began practicing these skills in the real life situation he faced.

3. A willingness to seek out other parents of similar needs and bring these parents together in a mutual support group that would survive over a period of months or years.

Report of Action Taken

Week 1. An initial meeting was held with the parent to conduct the pre-interview to determine the parent's information needs and skill development needs, and to establish an agreed upon plan of action. The pre-interview assessed his level of knowledge regarding family values, child's needs, available services, possible creative solutions, and advocacy skills.

Week 2. Discussion centered on the parent's aspirations for the child and brainstorming of possible opportunities for housing, schooling, health care, transportation, and recreation.

Week 3. An examination of the child's existing health and education records was conducted. The health care component of her community living plan was drafted.

Week 4. Two fully inclusive schools in a school district 100 miles away were visited. Two other parents of children presently in institutions were included for the visits. A follow-up meeting was held with all three parents to debrief on the visit, to consolidate the information they had gained regarding inclusive schooling, and to explore ways to translate their desire for inclusive schooling for their children into the reality. The education component of the community living plan for the daughter of the single parent father was drafted.

Week 5. One of the parents who had attended the school visits initiated a meeting of any parents in the immediate area whose children were in the institutions, to discuss progress and problems associated with the deinstitutionalization process. With encouragement and support, the single parent father attended that meeting. Later that week, he and the two other parents travelled together 250 miles away to visit a community residence for children who had previously lived in an institution.

Week 6. A follow-up meeting was held with all three parents, plus two others, to debrief on the visit, to consolidate the information they had gained regarding small community residences for children, and to explore ways to translate their desire for similar housing for their children into the reality. The residential component of the community living plan for the daughter of the single parent father was drafted. The health and education components were reviewed and revised.

Week 7. Recreation and leisure opportunities in the community were explored along with the necessary transportation requirements. The recreation /leisure and transportation components of the daughter's community living plan were drafted. The parent asked for and with some support and preparation, attended a meeting with senior officials of the Department of Community Services to discuss his ideas for his daughter's community living plan. A follow-up session was held to debrief on the meeting and to reinforce his beginning advocacy skills.

Week 8. The parent group decided to continue to work together as a group, and invited various professionals in the community to assist them in their activities. Five professionals, including the writer, willingly agreed to support this group. The meeting this week focussed on their feelings of powerlessness and the enormity of the task of getting the appropriate

supports in place for their children to return to the community. The single parent father shared his experience since being involved with the practicum and his growing optimism that he would be able to achieve what he wants for his daughter. In addition, three parents, including the single parent father, visited the local residential services agency to discuss how the parents' request for small (three or less children) community residences could be provided.

Week 9. The parent group met to discuss advocacy skills and to develop some advocacy strategies that could be implemented immediately. In an effort to raise public interest and support for the issues they faced, they agreed to initiate a letter writing campaign to their elected government representatives and to local newspapers all over the province focussing on the need for respite care services for families with a child with a mental handicap. To achieve greatest impact, they agreed to all write during the same week and to ask friends, neighbours, and relatives to do the same. The single parent father was an active participant in the discussions and decisions.

Week 10. The final draft of his daughter's community living plan was completed. The parent requested a meeting with the senior officials of the Department of Community Services to present the plan. Planning and preparation for the meeting was carefully coached. A follow-up meeting was held to debrief on the meeting, to review and reinforce his advocacy skills, and to celebrate his achievement.

Week 11. A meeting was held with the parent to conduct the post-interview to determine the parent's growth in information and skill development, and to identify any remaining needs. The post-interview

again assessed his level of knowledge regarding family values, child's needs, available services, creative solutions, and advocacy skills.

Week 12. Pre- and post-interview results were analyzed and compared. The parent group met to discuss the success of their first letter writing campaign and plan the second, to plan for formal presentations to the local school boards and to the Minister of Community Services. They agreed to formalize their group and to proceed with incorporation as a nonprofit organization. The single parent father was one of the strongest proponents of formalizing the group for mutual support and ongoing advocacy.

Summary

The implementation phase of the practicum progressed more smoothly than originally anticipated. The intention was to intervene with the identified single parent father, and others if they became available. It was not at all certain in the beginning that others would be identified or interested in participating. Fortunately it turned out that other parents were in need of similar support and agreed to participate in the practicum.

It is interesting to note that one informal strategy used in the intervention proved to be particularly beneficial. The parent was given the educator/counsellor's office and home telephone numbers and encouraged to make contact whenever he needed. Initially the parent called very frequently, and as he gained confidence in himself, the calls reduced dramatically. This kind of ready access to support seemed to be a critical factor in reducing the isolation and powerlessness felt by the parent.

CHAPTER V

RESULTS, DISCUSSION, AND RECOMMENDATIONS

Results

Introduction

The problem addressed in this practicum was that isolated parents of institutionalized children with mental handicaps were disconnected from support networks and felt unprepared for the task of working with government officials to develop a deinstitutional-ization or community living plan for their sons and daughters. The solution to the problem implemented in this practicum provided support primarily to one isolated parent. Individual counselling, information, and support comprised the intervention strategies utilized. A pre-interview and a post-interview were employed to determine the parent's growth competence in developing a community living plan for his daughter, knowledge of appropriate community services, and confidence in adocating for his daughter. The development of a community living plan designed to meet his daughter's specific needs was an additional product by which to measure the effectiveness of the practicum intervention.

Pre-Interview

The pre-interview with the single parent father revealed a profile of a man who was despairing and fearful of what the future held for his daughter, who lacked confidence in his own ability to plan and care for his daughter, and who was sceptical of the intentions of the government and of the advocacy organizations.

To the question "What do you want for your daughter/son? What would her/his life look like?" , the parent responded:

> I want Jody to live in the community. She belongs in the community. She is a real person and should not be stuck away somewhere. I want her nearby, not 150 miles away. I want her to go to school and to have friends. I want her to be happy and not cry every time I visit her or have to leave her. I want to look after her myself, but I know I can't do it alone. I tried and I couldn't do it. I don't think it will ever happen.

To the question "What are your daughter's/son's present needs?", the parent responded:

> She needs a place to live in the city so she can be near me. She needs to go to school and have friends like she did before. She needs better medical services. I want her off the damn medication [phenobarbitol] so she can stay awake. I want her to have the surgery on her feet so she can walk better. I want her to have the same things any other kid has. Just because she is handicapped they think they have the right to just put her away and forget about her. It makes me so angry and sad. I know what she needs but I don't know how to make them [government] do it.

To the question "What are the available services in your community?", the parent responded:

> Nothing! Institutions! There's adult community services but none for kids. There's nothing! No support for families. No respite care. Nothing!

To the question "Suppose the government agreed to put in place whatever you wanted, what would you want for your daughter/son?", the parent responded:

> They won't! They have made so many promises in the past and then broken them. I hate her being in the institution. I tried foster care and that was a disaster. I tried looking after her myself but I can't do it alone. I don't even know what to ask for, and even if I did ask, they would dilly-dally around and never do it. They don't care about our kids. They just want to close the institutions to save money.

To the question "The government has asked the parents to prepare an individual community living plan for each of your children. What do you think should be in the plan for your daughter/son?", the parent responded:

> I don't even know where to begin. I can't do it - but I am afraid to let them [government] do it. They don't really know her. They don't care about her. I'm her father and I want to have control over what happens to her, but I just don't know how.

To the question "What have you done so far to try to get the government to address your needs and your daughter's/son's needs?", the parent responded:

> Every time I meet with the people from Community Services, they are so ignorant and uncaring, I get angry and end up in a fight with

them. They hate to see me coming. Then I go home and cry in desperation. It's just no use anymore. There's no point in me going back again.

To the question "How have the parent groups or advocacy associations been helpful to you?", the parent responded:

> They are useless! I went to the [institution] parent group meetings a few times, but they [the parents] are only interested in their own kid. And it's mostly mothers. They don't understand what it's like for me with no one to help me. Besides, that group is really being controlled by the institution staff who want to keep the institution open. And the [provincial advocacy association] is doing hardly anything to make the government give us the money and services we need to have our kids in the community. They cave in on everything the government does. There's nobody out there to help me.

To the question "How do you think I could help you?", the parent responded:

> I am really scared the government is going to take over and do whatever they want with her. I need someone to help me do the [individual community living] plan so that I at least have some input into what they do. I can't let them keep on controlling her life.

Outcome Results

The following specific outcomes were projected for this practicum.

Outcome 1. After the practicum implementation, the isolated parent(s) of each child will have prepared a suitable community living plan.

The single parent father engaged in information gathering, brainstorming, and decision making to develop a suitable community living plan for his daughter. In the planning process he described her strengths and needs, his ideas for appropriate services, looked at available services, and generated ideas for creative new services. The plan components included health (general physical health, medications), communication (speech, hearing, vision), behavioural patterns (psychological health, behavioural/attitudinal), self-care (personal hygiene, home management), community integration services (health, education, recreation, residential support/friends, special training programs, transportation, volunteers, traffic safety, stranger awareness, worship), and housing and support staff. While the plan might have been organized somewhat differently, it was felt that it was preferable at this time to use the categories and format set out by the Department of Community Services. The details of the plan can be found in Appendix C.

Outcome 2. After the practicum implementation, isolated parents will be familiar enough with the available services to have made appropriate choices and decisions for and with the child.

The single parent father, along with two mothers, visited two inclusive schools in the province as well as three schools in their local area. They also visited a new small community residence for three children in a distant part of the province as well as meeting with the local residential services agency. Armed with the evidence that what they wanted for their children was within the realm of possibility, the single parent father was able to successfully design an appropriate housing and support component of the community living plan.

Outcome 3. After the practicum implementation, the isolated parent(s) will have attended at least two group parent meetings.

In the fourth week of the implementation, the single parent father visited two schools in another district. He was agreeable to including two other parents on the visit. The following week, one of the parents invited a group of parents to meet to discuss their common concerns. The single parent father attended. As the weeks progressed, he became more comfortable, participated freely, and began to take on a leadership role within the group.

Outcome 4. After the practicum implementation, the isolated parent(s) will be empowered to retain the parental role of primary advocate and decision-maker for and with their child.

The formation of the parent group in week eight with the support of several professionals in the community proved to be a valuable tool in empowering the parents. They focussed on developing strong advocacy skills and put them into practice immediately. In addition to the public awareness advocacy, each time a parent had to meet with a government official, they met with the group first to plan for and practice, through role-playing, how to maintain control of their meeting and achieve their goals.

Outcome 5. After the practicum implementation, the isolated parent(s) will have participated with government officials in at least two meetings regarding the planning of services for their child.

In week seven the single parent father met with officials of the Department of Community Services to discuss his ideas for his daughter's return to the community. He stated his case well and remained calm and in control throughout the meeting. In week ten, he again met with the officials to present the community living plan he had developed for his daughter. The plan was well received and was praised for its clarity and comprehensiveness. The government officials stated that "this was the type of plan they should be using in the future". The single parent father was confident and proud of his accomplishment.

Outcome 6. After the practicum intervention, a new and successful model of intervention for supporting isolated parents in the deinstitutionalization process will have been demonstrated.

The model of intervention used in the practicum included information, individual counselling, and support. The information gathering was extensive in the early weeks. Personal visits to model education and housing services were critically important. The parents were familiar with the requisite health care services, but had only limited verbal or written information regarding education and housing services. They were unable to visualize the reality of those services and hence doubted their quality. The experience of site visits was invaluable. The individual counselling was also extensive in the early weeks and focussed on building the father's confidence in himself, on evaluating existing services, and on learning such advocacy skills as preparing for important meetings by careful planning, having a specific goal clearly in mind to be achieved at the meeting, and remaining calm and in control. Support during the information gathering process and the development of the

individual advocacy skills stages took the form of individual meetings with the single parent father and later with the newly formed parent group. The availability of the counsellor by telephone at any time was perhaps the most important factor.

Post-Interview

The post-interview with the single parent father revealed a profile of a man who was cautiously optimistic about his daughter's future, who was a willing participant, and at times a leader, in a parent support group, who had reasonable confidence in his own ability to plan and advocate for his daughter, but who remained somewhat sceptical of the intentions of the government.

To the question "What do you want for your daughter/son? What would her/his life look like?" , the parent responded:

> I want the same thing I have always wanted for Jody. I want her to live in the community, somewhere near me so we can visit often. I want her to go to a regular school with the supports she needs and I want her to have friends at school and in her own neighbourhood. I want her to have a regular life. Not all this "special" crap that only makes her more different, more separate from everybody else. Her life should be like any other teenager's except she needs some help and support to be able to do it.

To the question "What are your daughter's/son's present needs?", the parent responded:

> Jody needs a house or apartment in the city that she can share with one or two other teenagers and a caring staff for support. It has to be near a city bus route so she can get around easily. She needs to

go to her neighbourhood school so she can walk to school with her classmates and have friends. The school has to provide the support for her individual education plan too. She needs to have her hands and feet looked after by the specialists and to get off her medications so she isn't so drowsy all the time. She needs to be able to go to the movies, or shopping at the mall, or swimming or whatever she wants to do. Jody just needs the supports to be a real person.

To the question "What are the available services in your community?"' the parent responded:

The residential system in the city doesn't have children's houses yet, but I have talked to them and the government is negotiating with them, and it looks like they will be starting them soon. There is one junior high school in the city that is a fully inclusive school. Jody will have to live in that neighbourhood to be able to go there or else I will have to start negotiating with the school wherever she is going to be living, to provide the supports she needs. They might have to start a "Circle of Friends" for her when she first starts there like they did when she went to school in the city before. But that shouldn't be any problem. The medical things can all be looked after at the hospital in the city. That's where she went before she went away. Transportation is no problem. Jody and I take the buses all the time when she is home on weekends.

To the question " You have now completed an individual community living plan for your daughter/son, how will you go about ensuring that it is implemented?", the parent responded:

Well, I have already met with the residential agency people, and I have another meeting with them at the end of the month. I met with

the principal of the junior high school. She said Jody could only go there if she lived in that neighbourhood. So now I have to see where the residential agency will put the house. It won't be easy, but I guess I just have to keep meeting with them until I get what I want. I know if I don't fight on my own and through the parent group, the picture I have for Jody will never be a reality.

To the question "How have the parent groups or advocacy associations been helpful to you?", the parent responded:

I guess you were right. There are things that a group can do that you can't do by yourself. And the other parents have been good at supporting me when I needed it, and I have been able to support them too. We share a lot of things that we have learned and learn from each other. We are getting good at holding our own in the meetings with government. I think we were all frustrated with the institution parent groups and the [provincial advocacy] association. Now that we have formed our own group, things are a lot better.

To the question "What has been most helpful to you in the planning process we have gone through in the past three months?", the parent responded:

I have a picture now of what I want it to look like for Jody - but I don't believe that is what it will really look like in the end. It seems like they [government bureaucrats] are working against me, not with me. That's why the picture was foggy for so long. But now I know what I want, I am not afraid to meet them head on - and not lose my cool - and I know I have people to support me in the fight. And I also know that I am strong enough to help support the other parents who are not as far along in the process as I am.

To the question "What is left to do?", the parent responded:

> I don't trust the bureaucrats that what they say will happen will really happen. I'm afraid they are going to nickle and dime it to death. They are more interested in the house than they are in the supports Jody needs around her to live successfully in the community. I'm just going to have to keep on fighting to make sure that Jody gets what she needs, that they don't back down and just dump her in the community, or change their minds and keep the institution open. I won't let that happen, and neither will the parent group. We are strong now and the government is paying attention to us. So we have to keep on and see this through for all the kids.

To the question "How do you think I could continue to help you?", the parent responded:

> Just stay with the parent group. We still need support from you [professional] people. There's still a long way to go to get the rest of the kids out and those places closed down....For me, well, I just need to be able to call you and talk things over when things get rough (laughs) - not like before when I was on the phone to you all the time!

Analysis of Results

The responses given in the pre-interview revealed a father who felt pessimistic and helpless in his desire to improve the life situation of his daughter. He did not know "what to ask for", "where to begin", and he believed that there was "nobody out there to help me" and that "it would not happen".

Following the intervention, the responses given in the post-interview revealed a father who felt more optimistic and empowered and had taken substantial action to improve the life situation of his daughter. His desires for his daughter had remained unchanged, but he articulated them with greater clarity and specificity. For example, his description of his daughter's housing needs changed from "live in the city so she can be near me" to "a house or apartment in the city...share with one or two other teenagers...caring staff for support...near bus route". His description of his daughter's schooling needs changed from "go to school so she can have friends" to "go to her neighbourhood school...walk to school with her classmates...provide support for her individual education plan".

The father's knowledge regarding the available services in the community changed as well. Between the pre-interview and the post-interview, his description of available community services changed from "nothing! nothing!" to "the residential system doesn't have children's houses yet...I have talked to them...government is negotiating...looks like they will be starting them soon"; "junior high school...fully inclusive...have to live in that neighbourhood or...have to start negotiating with the school wherever she is going to be living to provide the supports she needs...start 'Circle of Friends'...shouldn't be any problem".

Evidence of a transition from helplessness to positive action is also noted. Pre-interview reponses such as "I don't know what to ask for", "I don't know where to begin", and "there's no point in me going back again" changed to "I have already met with the residential agency...another meeting...at the end of the month", "met with the principal of the junior high school", "I just have to keep meeting with them until I get what I want".

An alteration in the father's view of the role of advocacy is indicated by the following. When asked in the pre-interview how parent groups or advocacy associations had been helpful, he responsed "useless!", "they don't understand what it is like for me", "doing hardly anything", and "they cave in on everything". Following the intervention, he responded "there are things that a group can do that you can't do by yourself", "other parents...good at supporting me", "I have been able to support them too", "we are getting good at holding our own in the meetings with government", and "now that we have formed our own group, things are a lot better".

In reviewing the intervention process, the father described his own growth both as an individual advocate for his daughter and as a general advocate for others in similar circumstances. Responses illustrating this point include, "now I know what I want, I am not afraid to meet them [bureaucrats] head on - and not lose my cool - and I know I have people to support me", "I am strong enough to help support the other parents who are not as far along in the process", "we have to keep on and see this through for all the kids".

Summary of Results

In summary then, after the successful implementation of the practicum, one of the previously isolated parents, the single parent father, was able to participate meaningfully in the development and implementation of the community living plan for his daughter and was well on his way to becoming a strong advocate for her. In addition, he felt conficent enough to provide support for the other parents in similar circumstances, and to advocate for those children in the institutions who were wards of the province and had no families to speak for them.

The other parents who formed the support group were at varying stages in the development of plans for their children. None of the parents any longer felt isolated, and all were more confident in their own abilities to make informed judgements about their children's needs and services, and were becoming strong advocates for their children.

Discussion

The success of the intervention may well be related to the fact that the strategies were drawn largely from the literature. Goldfarb et al. (1986) recommended beginning with an evaluation of parents roots, values, and strength to cope. This was accomplished by means of the pre-interview.

The three main intervention tools employed were information gathering, individual counselling, and support. Information gathering was a successful strategy consistent with the recommendations of Black et al. (1985), Kraus (1986), and Summers et al. (1989). Facilitating the development of advocacy skills through individual counselling was consistent with the suggestions made by Berger and Foster (1986), Goldfarb et al. (1986), and Krauss (1986). Assisting in the development of support through access to and participation in social networks and parent self-help groups was consistent with recommendations stated by Berger and Foster (1986), Goldfarb et al. (1986), Meyer (1986), Parke (1986), Suelzle and Keenan (1981), and Summer et al. (1989).

For the single parent father, his initial needs were met not only by the individual counselling sessions, but also by having the special

education consultant/ counsellor available to him whenever he needed to talk. While ten phone calls the first week and twelve the second might at first glance seem excessive, it apparently was a critical factor in reducing the isolation felt by the parent, a pressing need noted by Suelzle and Keenan (1981), and in restoring his trust in professionals, a requirement specified by Goldfarb et al. (1986). The remaining pattern was very interesting in that there were three phone calls in the third week, and only one or none each week thereafter. This supports the flexible approach described by Taylor et al. (1989) which uses a "whatever it takes" policy to support families.

The flexible approach was also illustrated in capturing the opportunity to link the single parent father with two other parents to make the first visits to the schools. This opened the door to his being invited to the first meeting held by the group. The willingness of the counsellor to accompany the single parent father to that first meeting and to remain as one of the professionals to provide support to the group was a further indication of the adaptable approach required for this intervention.

The growing empowerment of the single parent father and the other members of the parent group was impressive. Although the path was not always smooth, the set-backs were usually in the form of a meeting with some agency or government official that was not fully satisfactory, but these were minor in nature. The parent group, albeit newly formed, was particularly good at supporting each other and confidence was quickly restored.

Since the completion of the implementation phase of the practicum, the parent group has become formally incorporated as a nonprofit organization called the CTC Family Support Group, with the single parent

father's signature on the incorporation document as a charter member. The Minister of Community Services has struck an advisory committee on the closure of the Children's Training Centers with various categories for membership on the committee. Five of the parents from the parent group, including the single parent father, successfully described their roles to fit the designated categories and now sit on the Minister's committee. Their confidence and courage continues to grow.

Recommendations

1. When parents are isolated and unable to engage in the typical models of group support and counselling, it is recommended that individual counselling be employed and that the counsellor be fully available to provide extensive support as required.
2. It is recommended that interventions take a flexible "whatever it takes" approach especially in the beginning. This includes being alert to and capitalizing on any possible opportunity to assist an isolated parent in establishing contact with other parents in similar circumstances, and providing whatever support is necessary to cement the relationship.
3. It is recommended that support be continued during the period that new advocacy skills are being tried out in real life situations. Coaching and debriefing are essential.
4. It is recommended that successful advocacy events be celebrated with the individual or group to reinforce their strengths and acknowledge their empowerment.
5. It is recommended that the counsellor remain involved with the parent group to provide support and encouragement until the deinstitutionalization process is complete for these parents, and their children are returned to the community with the services and supports they need.

Dissemination

The practicum results have been shared with the parent group. Not only was it of interest to them, but it proved to be very confirming of their new strength, courage, and empowerment - something they had not previously fully recognized.

The practicum results will be shared with colleagues in the School of Education who teach in the Master of Education in Counselling program. It is expected to be of value to their students. It will also be shared with the provincial advocacy association as it may be helpful in their continuing efforts to support parents elsewhere in the province. Application has been made to present the practicum results at the provincial advocacy association conference in the spring of 1993.

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Appendix A

Pre-Interview Guiding Questions

1. What do you want for your daughter/son? What would her/his life look like?

2. What are your daughter's/son's present needs?

3. What are the available services in your community?

4. Suppose the government agreed to put in place whatever you wanted, what would you want for your daughter/son?

5. The government has asked the parents to prepare an individual community living plan for each of your children. What do you think should be in the plan for your daughter/son?

6. What have you done so far to try to get the government to address your needs and your daughter's/son's needs?

7. How have the parent groups or advocacy associations been helpful to you?

8. How do you think I could help you?

Appendix B

Post-Interview Guiding Questions

1. What do you want for your daughter/son? What will her/his life look like?

2. What are your daughter's/son's present needs?

3. What are the available services in your community?

4. You have now completed an individual community living plan for your daughter/son, how will you go about ensuring that it is implemented?

5. How have the parent groups or advocacy associations been helpful to you?

6. What has been most helpful to you in the planning process we have gone through in the past three months?

7. What is left to do?

8. How do you think I could continue to help you?

Appendix C

INDIVIDUAL COMMUNITY LIVING PLAN

Name : Jody F.
DOB : 24 August 1978

Parents: Robert F.
Halifax, Nova Scotia

BACKGROUND HISTORY

GENERAL HEALTH (PHYSICAL)

Jody is generally a healthy child of small stature for her age. Although she had many medical problems as an infant and preschooler, in recent years she enjoys relatively good health.

1. Seizures : No seizures have been observed by either parent since Jody was three years old. There have been rare occurrences reported by CTC (Children's Training Center institution) staff in recent years. Jody's last reported seizure was in April 1991 at which time her medication was slightly increased by Dr. C. It is questionable how much of Jody's falling is related to seizures and how much to her foot and gait problems (discussed later).

Needs : Jody needs a follow-up assessment with Dr. C. including an EEG with a view to reducing medication to better balance her seizure control and excessive sleepiness (discussed later).

2. Bowels : Jody has no problems with her bowels provided she maintains an adequate diet and exercise.

Needs : Jody needs a well balanced diet with sufficient roughage and reasonable physical activity and exercise.

3. Bladder : Jody had a bladder infection in October 1991. None others are noted.

Needs : Jody needs to avoid using scented bath products and to be sure the tub is well cleaned before she uses it.

4. Allergies ; Jody has a severe allergy to peanuts and all related peanut by-products. Her allergic reaction to peanuts is expressed as nasal and throat congestion and swelling which might potentially lead to blockage of her windpipe. Antihistamine injections have never been required nor kept on hand.

Jody has a mild allergy to smoke and some perfumes (especially Yardley's) which is expressed by nasal stuffiness and sneezing. Some allergy to pollen and feathers have been reported but have not been observed by parents.

Needs ; Jody must not eat any foods containing peanuts or peanut by-products including peanut oil. She should avoid exposure to the other noted allergens as much as possible. Seldane tablets need to be available to counteract any allergic reaction.

5. Skin ; Jody frequently has dry skin on the inside of her wrists and the outside of her elbows. Occasionally small patches on her face become very dry, cracked, and itchy. Jody tends to develop dry scalp when the same brand of shampoo is used for a long period of time.

Needs : Jody needs to use her prescribed cortisone cream as required on her dry skin areas. Also, every month she needs to change the brand of shampoo she uses.

6. Feet ; The toes on both Jody's feet are malformed and unusually positioned. Jody walks with a very wide stance and places her full foot down with each step. She is not able to walk rolling from heel to toe.

Needs ; Jody needs a reassessment of her feet with an orthopedic surgeon with a view to possible surgery to improve her gait.

7. Hands : Many of Jody's knuckles on both hands seem fused and cannot bend. This interferes with her ability to perform important fine motor tasks such as buttoning, zippering, signing, etc.

Needs : Jody needs a reassessment with an orthopedic and/or plastic surgeon with a view to possible surgery to improve her fine motor ability.

8. Chest : Jody had a bronchial asthmatic condition as a preschooler and used a ventilator as required. This problem has not existed since she was five years old. In recent years Jody has had only occasional colds and flus which may go to her chest if untreated.

Needs ; When Jody has a cold she needs to be seen by her pediatrician early for preventive treatment as required.

9. Ear, Nose, and Throat : Jody had frequent ear infections as a young child and had tubes in both ears. In recent years she has had only occasional ear infections, usually associated with a head cold. Jody is not yet able to blow her nose effectively and tends to clear her nose, if at all, by sneezing. It seems that being unable to clear her nose properly increases the likelihood of the infection spreading to her ears, throat, and chest. Jody has frequently had antibiotic treatment for these infections.

Needs ; When Jody has a cold or flu, she needs to be seen by her pediatrician early for preventive treatment as required.

10. Eyes ; As a preschooler, Jody wore a patch on her left eye for about one year to strengthen her lazy right eye. Her vision was considered to be good otherwise. Jody seems to have exceptionally good peripheral vision. Jody has a droopy right eyelid which is especially noticeable when she is tired. Jody was being followed annually by Dr. L., pediatric ophthalmologist at the IWK. Jody has not been seen by him in the last five years.

Needs ; Jody needs to have her vision reassessed by Dr. L.

11. Skull ; Jody had skull surgery to allow for adequate growth as an infant. Her skull grows normally now and is no longer a problem.

Needs : None noted.

12. Sexual Development : Jody's physical development is typical for her age of thirteen years. Menstruation has not yet started.

Needs : Jody needs to learn about her maturing body and prepare for menstruation.

13. Teeth : Jody has had annual check-ups with the dentist since she was a preschooler. She has had no dental work done to date. Jody still has most of her baby teeth, as well as some second teeth. Her oral hygiene is done daily with assistance.

Needs : Jody needs a full dental assessment with sufficient support and practice to be able to accomplish this without anaesthetic.

Medications

Jody is able to take liquid or tablet medication by mouth as required. She has no known allergy to any medication.

1. **Phenobarb** 45 mgm. morning and evening. For seizure control.

2. **Westcort Cream** 0.2% applied sparingly 3 times a day as needed. For dry skin patches.

3. **Seldane** (over the counter) as needed. For mild/moderate allergy symptoms.

Communication

1. Speech : Jody has a strong desire to communicate with others and works very hard to do so. While her speech is limited to a single repetitive vocalization produced on request, she spontaneously uses sign language, gestures, and facial expression to communicate her interests and needs. In her early school years Jody was introduced to Blissymbolics with limited success. Prior to moving to the CTC, Jody was assessed at her public school for adapted computer assisted communication.

Needs : Jody needs a complete speech and language assessment with a view to improving her speech as much as possible, to improving communication through expanding her sign language ability, and to exploring computer assisted communication as a viable option. Jody needs to have people in her home and school environments who can communicate with her through the methods that she finds most successful.

2. Auditory : Despite earlier problems with ear infections, Jody has no apparent hearing difficulty. She hears and comprehends what is said to her.

Needs : Jody needs a reassessment of her hearing as part of a comprehensive communication assessment.

3. Visual : Despite earlier problems with her eyes, Jody seems to have good vision, particularly peripheral vision, and is very attentive to what is going on in her environment.

Needs : Jody needs to have her vision reassessed by Dr. L., pediatric ophthalmologist at IWK.

Potential for Community Living Adjustment

Jody has always adjusted well to new situations. She enjoys people and has a very trusting nature. While she obviously misses living with her family, she accepts the situation quite well. Living closer to her family will no doubt be more enjoyable for her.

DESCRIPTION OF CHILD'S BEHAVIOURAL PATTERNS

Psychological Health

1. Urine Incontinence : This has recently been expressed by CTC staff as a problem. However, since it has only occurred around the time when Jody had a bladder infection in the fall of 1991, this is not considered a serious problem. Jody will occasionally lose control of her urine in circumstances where she is tickled or is enjoying a prolonged giggle. Otherwise, this is not an issue at this time.

2. Stubbornness : This has recently been expressed by CTC staff as a problem. Jody can be stubborn and refuse to comply with a request at times. This is infrequent and not unlike most children, especially young teenagers. With limited speech, Jody must find other ways to communicate her views. Stubborn refusal to comply serves that purpose. Jody does not engage in this behaviour excessively and it is not considered a problem.

3. Sleep : It has recently been reported by CTC staff that Jody requires a nap every afternoon. It is unclear why this is seen as a mental/emotional need. However, Jody does seem to need an excessive amount of sleep for a child her age. How much the phenobarbitol contributes to this needs is not known at this time.

Needs : As noted elsewhere, Jody needs a reassessment of her seizure management with Dr. C. with a view to reducing the medication to better balance the seizure control and the excessive sleepiness.

4. Social/Emotional State : Jody is a very capable young teenager and understands much more than she can express. She is generally happy, loves having people around her and doing things, and willingly participates. Jody lets you know by the expression on her face what she likes and dislikes, who she likes and who she dislikes. She is very sensitive to the emotions of others and can respond appropriately, either to share a joy or console a sadness. Jody responds appropriately to her

own circumstances, although sometimes intense emotions become mixed; for example, she might laugh and cry together.

Behavioural / Attitudinal

1. Discipline : Jody seems to appreciate and benefit from clear, consistent expectations and a reliable structure. She responds well to praise and encouragement. She works hard for an anticipated reward. She can take responsibility for her own actions; for example, cleaning up a mess she has made. Jody responds well to a verbal reprimand, loss of a privilege, restoring the environment to order, or a brief time out (five minutes) as required.

Needs : Jody needs an environment that provides clear, consistent expectations, frequent and appropriate positive reinforcement through verbal praise and occasional rewards. When punishment is required, it should take the form of verbal reprimand, loss of privilege, or brief (less than five minutes) time out.

2. General Socialization : Jody enjoys being around people and behaves appropriately in all social situations whether it is at home, or at school, or visiting relatives and friends, or eating in a restaurant, or going to a hockey game, movie, amusement park, Winter Fair, or whatever.

Needs : Jody needs more opportunity to engage in the normal social activities expected for a young teenager rather than just the weekend activities described above.

3. Relationship with Family Members : Jody loves being with her family and is always reluctant to leave them to return to the CTC. Jody knows she is loved by her family and responds to it.

Needs : Jody needs to live nearer her family so that she can visit more often.

4. Special Interests and Preferences : Jody likes all activities that involve interaction with other people. Sitting watching television is not high on her list of priorities. She loves to be on the go - anywhere - and will happily go by car, by bus, or walk, although she tires when walking a long distance. Jody enjoys animals, especially dogs. She loves music, both listening and playing the piano or electronic organ.

DESCRIPTION OF CHILD'S SELF-CARE SKILLS

Personal Hygiene

1. Personal Hygiene : Jody goes to the bathroom without assistance. She occasionally needs to be reminded to go and always needs assistance after a bowel movement.
Jody brushes her teeth and needs assistance to properly brush all teeth. Jody has difficulty reaching the top of her head. Therefore brushing or washing her hair requires assistance.
Jody washes her face and hands with no assistance.
Jody can bath herself, but usually requires verbal prompting to wash thoroughly.

Needs : Jody needs to continue to develop her self care skills.

2. Eating : Jody makes appropriate food choices. Typically she eats a small breakfast and regular lunch and supper. If they are visible, she asks for snacks, especially junk food and chocolate, but otherwise does not seem to care about snacks. Jody eats well at the table, chewing well and keeping her place neat. Jody needs to have her meat cut for her and hard fruits and vegetables (apples, raw carrots, etc.) need to be cut into sticks or wedges.

Needs : Jody needs to continue to develop her self care skills.

4. Dressing : Jody can dress and undress herself with the exception of tying laces, buttoning, or starting a zipper. Because of the limited flexibility in her hands and shoulders, it takes Jody longer than usual to

dress herself. Jody can put on her boots, although she may need verbal prompting to get them on the correct feet. Jody refuses to wear mittens.

Needs : Jody needs to continue to develop her self care skills.

5. Ambulation : Jody walks independently but tires with distance. Due to the physical problems with her feet, Jody has a somewhat awkward gait , but rarely falls. Jody does not run or jump.

Needs : Jody needs an assessment of her foot problems and continued opportunities to build and strengthen her stamina and fitness level.

6. Sleeping : Jody sleeps more than is typical for her age but this may be due to the medication she is taking.

Needs : Jody needs a reassessment of her present medication schedule and an opportunity to build her stamina so that she can enjoy a full length of day.

Home Management Skills

1. Meal Planning/Preparation :

Jody can take food out of the refrigerator and replace it as requested. The same applies to foods placed in cupboards at her level of reach. She can help set the table. She can select a knife, fork or spoon from the drawer as requested, but has difficulty in selecting several items and setting them at the proper places on the table. Jody clears the table successfully and places the dirty dishes in the sink. Jody has not yet had experience with cooking using the stove. Jody helps successfully with stirring activities; for example stirring lemon pie filling, or pudding, or sugar in coffee, or macaroni and cheese dinner etc. Jody prefers to wash the dishes after a meal but she also can do a reasonable job of drying the dishes. She puts away those dishes that belong in places that she can reach.

Needs: Jody needs further experience in the kitchen and to learn more of the meal preparation skills.

2. Room Management/ Household Cleaning :

Jody makes her bed every day with some assistance. With verbal prompting, she tidies her room each evening before going to bed. When finished with an activity, for example, books, videotapes, music instrument, tapes etc., Jody will clean up and put away her things with verbal prompting.

Needs ; Jody needs to become more independent with these skills and require less prompting. Jody could start to learn to use a lightweight vacuum cleaner and other similar household chores.

3. Laundry :

Jody likes to help with doing the laundry at the laundromat. She helps with gathering and sorting the clothes, putting them in the washers and dryers, inserting the coins, folding the clothes and putting them back in the baskets. Some verbal prompting is required.

Needs ; Jody needs to learn to complete the task with less prompting and to measure the soap, and to refine her folding technique.

4. Time Management :

Jody has some beginning understanding of the concept of time. She understands such things as later, in a little while, yesterday, tomorrow. Longer periods of time may not be as well understood by her.

Needs ; Jody needs to expand her knowledge of time and begin to read clocks both digital and analog. She needs to have the opportunity to makes choices about how she spends her time, to begin to understand how to manage her time independently.

5. Decision Making :

When given choices, Jody can makes decisions in many areas of her life. She decides on food choices, clothing, leisure activities, modes of transportation, bedtime, friends to be with, music, videos, etc.

Needs : Jody needs opportunity to makes decisions in all areas of her life except those areas that would leave her at risk for being harmed.

Community Integration

1. Health Services :

Jody has been involved with several health care specialists:

Pediatrician : Dr L. M.
Neurologist : Dr. P. C.
Ear Specialist : Dr. C.
Ophthalmologist : Dr. L.
Dermatologist : Dr. G.

Jody needs referrals to the following specialists :

Dentist : Dr. D. M.
Orthopedic Surgeon : Dr. D.B.
Plastic Surgeon : Dr. M. K.
Occupational Therapist :
Speech/Communication Therapist :

2. Educational Services :

Jody needs to be educated in her neighbourhood school in regular classes with her same age peers with the necessary supports for her to benefit appropriately. For the 1992-93 school year Jody would have an individual education plan and be supported in a grade seven or eight class.

3. Recreational Programs :

Jody needs to participate in such activities as are customary within the neighbourhood where she will be living. She needs to be able to participate in activities that she has already expressed an interest in, such as swimming and dancing.

4. Residential Support Services :

Jody needs a circle of friends who are her own age and who can include her in the typical teenage leisure and recreational activities.

5. Special Training Programs :

Jody does not need special training programs or special camps at this time. Jody needs to be supported to take advantage of the usual municipally operated recreation and leisure programs that are of interest to her and that are available to all teenagers.

6. Transportation :

Jody needs to live within walking distance of her school and the public transportation bus routes.

7. Volunteer Services :

Jody has not yet been involved in a community volunteer program. As she matures she needs to be encouraged and supported in becoming a community volunteer, perhaps in a senior's residence or a hospital.

8. Traffic Safety :

In the city, Jody is aware of sidewalk boundaries and has never stepped off the curb alone. She has always been accompanied by someone when crossing the street. Jody is becoming aware of the signs to attend to when crossing the street, such as traffic lights, crosswalk markings, etc.
Jody's ability to respond immediately to urgent commands like "stop" or "put your hands down" protects her from potentially dangerous situations in traffic or in the kitchen etc. While Jody needs to learn more about working in the kitchen, she does not actively put herself in danger at this time.

9. Additional Areas of Concern :

Jody has not yet had the opportunity to learn appropriate stranger awareness skills. She is openly trusting and friendly with strangers which leaves her very vulnerable. Jody needs to learn the appropriate social distance boundaries, particularly the difference between what is acceptable behaviour with friends, and what is acceptable behaviour with strangers.

10. Public Worship :

Jody has not had much experience with formal attendance at church. At this stage in her life, she would probably enjoy participating in her neighbourhood church, perhaps getting involved with a youth group.

PROJECTION OF REQUIRED SERVICES

Home : Jody needs to live in an ordinary neighbourhood house or apartment within walking distance of public transportation and her school. No other services, for example respite care to other families, should be provided in her home.

Housemates : Jody would be best situated with two other female housemates. Each person needs to have her own bedroom and share the common living space, kitchen, bathroom, living room.

Support Staff : Support staff must be female, and appropriately trained through a recognized training program. Personal characteristics such as warmth, caring, and sensitivity are essential, as well as the ability to provide a suitably structured and supportive environment for Jody to be happy, healthy and grow as a full member of her community. The girls/ young women living in the home and their parents need to be involved in the staff selection process.